

**Sickle cell disease (SCD)** is the most common inherited blood disorder in the United States, affecting an estimated 90,000 to 100,000 people. People with SCD can have a 20-30 year lower life expectancy.

## Improving quality of life

**The issue:** In the United States, 1,800 to 2,000 infants are born with sickle cell disease (SCD) each year and an estimated 90,000 to 100,000 Americans are living with SCD. SCD is the most common inherited blood disorder in the United States. Many suffer from debilitating pain, infection, stroke and organ damage. It can be a life-threatening condition with a 20-30 year lower life expectancy for people with the most severe form of SCD.

**Why it matters:** Social, economic, cultural and geographic barriers often limit access to comprehensive care, which contribute to the estimated \$2 billion in SCD healthcare costs in the United States each year.

**Solution and impact:** In 2015, the CDC Foundation and the Centers for Disease Control and Prevention's Division of Blood Disorders launched the Sickle Cell Data Collection (SCDC) program in California and Georgia to inform the development of a model for uniform, comprehensive care throughout the lifespan for people with SCD. The SCDC program equips states, health care provider networks and pharmaceutical and insurance companies with the information needed to establish cost-effective treatments and healthcare practices that improve and extend the lives of people with SCD. The SCDC program ensures that credible, scientifically sound information is available to inform policy and healthcare standards that improve health outcomes for SCD patients and reduce healthcare costs associated with the disease. The SCDC data will

**About us:** The CDC Foundation is an independent, nonprofit organization and the sole entity created by Congress to mobilize philanthropic resources to support CDC's critical health protection work. Since 1995, we have launched nearly 1,000 programs in more than 130 countries and raised over \$800 million through engagements with philanthropies, corporations, organizations, governments and individuals.

help inform ways that gaps in diagnosis, treatment and healthcare access for people with SCD can be filled by more effective policy, healthcare practices, and medications. The goal of the SCDC program is to provide the training and tools necessary for additional states to join the SCDC program, so that the data system incorporates information about people with SCD living throughout the United States.

**How you can help:** The CDC Foundation is pursuing support from multiple funders to expand the coverage of the SCDC program to additional states. In the future, the program may serve as a data collection model for additional U.S. states, other countries and even other rare diseases.

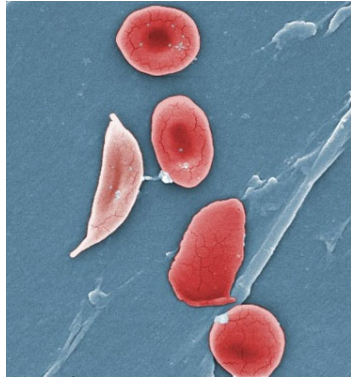
**Learn more:** To invest in CDC's efforts to improve the lives of Americans with SCD, or to learn more, contact Advancement at the CDC Foundation: [advancement@cdcfoundation.org](mailto:advancement@cdcfoundation.org), 404.653.0790.

## Scope of the problem



Care and treatment for SCD cost approximately  
**\$2 billion dollars** annually.

# Stories of impact: Improving the state of sickle cell disease



**You can make a difference:** Beyond federal support, investments by the philanthropic and private sector are essential to improving the lives of those suffering from sickle cell disease.

The Sickle Cell Disease Collection (SCDC) program has been implemented in California and Georgia, where health information is collected about people with sickle cell disease (SCD) to study long-term trends in diagnosis, treatment and healthcare access. Many important insights have resulted from this data collection which have helped to improve the state of SCD. The SCDC program has led to several areas of impact, including the following examples.

## California: Connecting SCD Healthcare Providers

Historically, SCD healthcare providers in California have had limited opportunity to collaborate to improve care outside of their own institutions or clinical settings. The SCDC program in California has developed relationships with hematologists and SCD care programs throughout the state during the data collection process. These relationships have increased opportunities for collaboration among healthcare providers serving the SCD population. Collaboration is critical to the exchange of knowledge related to managing SCD and can help to improve patient outcomes and quality of care.

## Collaboration is critical to the exchange of knowledge related to managing SCD.

The SCDC program in California has brought together diverse clinicians, even across states, to work on data analyses and publications relevant to patient care and outcomes. The program has also enabled the development of a statewide plan for improving care using SCDC data, involving providers, patient advocates and community based organizations.

"The connections we've developed have paved the way for more collaboration and communication across diverse clinical settings, community based organizations, and state agencies," says Susan Paulukonis, MA, MPH, SCDC in California program director. "We hope to speak with one voice and work toward common goals."

## Georgia: Educating Healthcare Providers

The SCDC program in Georgia is providing valuable insights that are educating healthcare providers about improving care for SCD. Ongoing SCD surveillance in Georgia has determined where patients with SCD live within the state and what services they are receiving, which is essential for identifying and addressing gaps. For example, SCDC data have highlighted disparities in services between urban and rural areas and between services for pediatric and adult patients.

County-specific data allow the SCDC program in Georgia to identify SCD hot spots and make healthcare providers aware of them. "The data highlight that SCD is a significant problem in providers' home towns. In my presentations, this is one of the most important slides to get providers' attention," said James Eckman, MD, professor emeritus, hematology and oncology, Emory University School of Medicine.

Dr. Eckman also uses mortality data in many presentations to dispel the myth that patients with SCD still die young. "SCDC data show that the prognosis for sickle cell disease has improved and that providers need to think about health problems unrelated to SCD that older patients may develop."

The SCDC program in Georgia has provided critical information to clinical care providers and those who advocate on behalf of SCD patients. The program has also developed a three-year action plan that includes strategies to continue using Georgia's SCDC data to help improve care for people with SCD.